- Do you have patients with a **chronic 'mystery illness'** that **defies conventional treatment** approaches?
- Do your patients suffer from *chronic fatigue*, complain of *migrating pain* and display *a multitude of unexplained symptoms*?
- Have patients presented with rashes and skin complaints weeks, months or even years after bites from ticks or other blood-sucking insects?
- Do you consider **borreliosis** and **other common co-infections associated with Lyme disease** in your differential diagnosis?
- Are you *relying solely* on Australian public health laboratories to determine your diagnosis, *even when a patient's symptoms are consistent with a Lyme-like illness*?
- Are you **confident** you know everything you need to know **to competently diagnose and treat Lyme disease or a Lyme-like illness and co-infections**?

## Are you prepared for Lyme disease?

Internationally, 'Lyme disease' has become the term commonly used to describe an infectious illness caused by *Borrelia* spp bacteria, as well as co-infections associated with the disease (such as babesiosis and bartonellosis). A more apt term, **Multi-systemic Infectious Disease Syndrome** (MSIDS), is preferred by WA Lyme Association (WALA) to describe the condition affecting its members.

Lyme disease is known to be spread by ticks, although other forms of transmission have yet to be fully researched. Borrelia species capable of infecting humans have been found on every continent, including Antarctica. Read more about Lyme disease: Transmission, Prevalence, Symptoms, Treatment, Diagnosis and Testing.

There is no doubt that Lyme disease (aka MSIDS) is *controversial* and tends to polarise the medical community regarding many aspects of its presentation, and nowhere more so than here in Australia

For the past twenty years, the Australian medical community's denial of Lyme disease has been defined by a single government-funded study that failed to find evidence of *Borrelia* spp in east coast ticks, but rather dismissed spirochete-like objects as artefacts, not worthy of further investigation. There has been no major research into Lyme disease in Australia during the interim period, although a number of studies are currently underway and there have been **numerous isolated findings of Borrelia** here since 1959.

While Borrelia burgdorferi has not consistently been found in Australian ticks or in human serology testing by Australian public health laboratories, it has become increasingly difficult to ignore the empirical evidence of a rapidly growing number of Australians whose clinical symptoms are consistent with Lyme disease. There are now thousands of patients who have been both clinically diagnosed with Lyme disease and whose diagnosis has been confirmed by positive Bb tests obtained through overseas laboratories.

## **Recent developments in Australia**

In 2013, in acknowledgement of Australians suffering from a Lyme disease-like illness, the Chief Medical Officer (CMO), Prof. Chris Baggoley, convened a Clinical Advisory Committee on Lyme Disease (CACLD) and commissioned a Scoping Study to identify appropriate research programs. Patient groups, including WALA, actively participated in this consultation process and in other **developments in Australian Lyme politics.** 

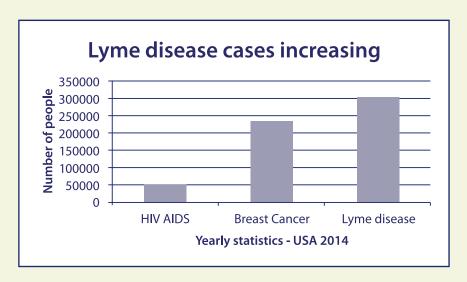
The CMO's recent **Progress Report** stated, "There is still no routine finding of *Borrelia* spp in ticks in Australia". Some medical publishers and commentators seized upon this to trumpet misleading bulletins: "No evidence of Lyme disease here". Whereas a more accurate interpretation is that the review process has been inconclusive to date and considerable further research has been highlighted by the CMO in his progress report.

The recommended research programs focus on identifying a causative pathogen, clarification of the discrepancies between Australian and overseas test results and gaining a comprehensive understanding of the Lyme-like illness presenting in Australian patients, as well as the epidemiology.

The Australian Government Department of Health's (DoH) **Scoping Study response** provides support for medical practitioners who find themselves faced with patients with myriad symptoms of unexplained aetiology recommending that "if patients present with repetitive episodes of sudden fever, myalgia, headache and nausea, relapsing fever should be considered, and although there is no evidence of relapsing fever group *Borrelia* species in Australia, the possibility of their actual presence should not be ignored both with respect to the normal relapsing species of *Borrelia*, but also *B. miyamotoi.*"

In a recent **media statement**, the CMO also highlights the lack of reliable "laboratory tests used to see if patients are showing an immune response to the bacteria that could cause this infection". He states "there are different approaches used by different laboratories ... which leads to different diagnoses for the same patients" and confirms the issues surrounding the diagnostic uncertainty, which necessitates that medical practitioners have better information about the clinical symptoms of Lyme-like illness.

Australia is embarrassingly ill-prepared for a potential epidemic that now competes with HIV AIDS and Breast Cancer in its prevalence in other Western countries.



Source: CDC 300,000 - http://www.cdc.gov/media/releases/2013/p0819-lyme-disease.html

Source: HIV AIDS – 50,000 - http://www.cdc.gov/hiv/statistics/basics/

Source: BC statistics - 232,670 -

http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-key-statistics

Lyme disease is not even a reportable illness in Australia and the only epidemiological and other patient data being gathered and reported upon at this stage is a survey conducted by the Lyme Disease Association of Australia (LDAA).

Consequently, Australian practitioners usually rely on American information sources and diagnostic criteria, which do not necessarily reflect the Australian patient's disease experience. For example, the above survey indicated than less than 50% of patients displayed the classic Erythema Migrans rash characteristic in American diagnosis. More than 50% reported that they had been diagnosed with one or more co-infections, most commonly *Babesia* and *Bartonella*.

What we *don't* know about Lyme/MSIDS in Australia could fuel a thousand research studies.

## We DON'T yet know:

- If Australia has a unique strain of Borrelia or another pathogen capable of causing Lyme-like illness symptoms;
- What vectors might be capable of transmitting Borrelia or another causative pathogen;
- The potential for human to human transmission (and the evidence to date suggests we really should know);
- Whether Australian public health laboratories are adequately equipped to provide 'world best practice' testing in regard to finding these pathogens;
- What a case definition for diagnosing Lyme/ MSIDS in Australia should include;
- What treatment protocols are most effective in eliminating the infection; and,
- What other treatments and complementary therapies are beneficial in healing those afflicted with Lyme/MSIDS.

In short, we don't fully understand what causes it, how to diagnose it or how to treat it. All of these gaps became evident in the DoH's review of Lyme disease which is **published on their web page**, for those who wish to read beyond the headlines.

Patients who are already suffering from the debilitating effects of Lyme/MSIDS cannot afford to wait for the years it will take research to be completed and for the Australian and WA governments to implement a responsible public health strategy to address the 'Lyme disease problem'

## What we DO know about Lyme/MSIDS:

- There are already many thousands of Australians suffering from a Lyme-like illness (MSIDS) with over 500 already diagnosed in WA;
- Patients who have been fortunate enough to find a doctor who is able to diagnose and treat MSIDS are already experiencing significant health improvements;
- As public awareness of 'Lyme disease' increases, the number of chronically ill patients who recognise their own symptoms will also increase, as will demand for medical practitioners who are able to diagnose and treat them:
- In Western Australia, this demand already outstrips supply and waiting lists for new patients to see doctors experienced in treating Lyme/MSIDS now extend out to almost 12 months;
- Scores of West Australians are mortgaging and borrowing to raise the funds necessary to attend treatment clinics overseas;
- There is no public health strategy in place to warn people about the potential risks of infection, nor how to prevent Lyme disease;
- There is no public health strategy in place to educate practitioners in how to diagnose and treat Lyme/MSIDS;
- We urgently need more health professionals who are willing to educate themselves about the diagnosis and treatment of Lyme/MSIDS to assist in meeting this demand; and,
- Lyme/MSIDS is not just a fad, nor a psychosomatic illness, that is simply going to 'go away'.

The CMO's progress report also recommends: "If a person who has been diagnosed with Lyme disease and does not respond to treatment or has relapsed, then the treating medical practitioner should consult with a medical practitioner who has experience in treating Lyme disease."

The WA Lyme Association invites you to broaden your knowledge and join other WA health professionals at the Lyme Awareness seminar to meet with, learn from and ask questions of the most experienced practitioners currently consulting with Lyme/MSIDS patients in WA.

Seminar information: wala.eventbrite.com.au WA Lyme Association: www.wala.org.au